



Dear friends,

There are 25 days before Parkinson Awareness Month starts on April 1st. *Have you thought about what you can do in the month of April to help raise awareness about Parkinson's in your community?* WPC encourages you do something each day of the month, even just posting an article on your social media pages is a great way to spread news. Posting Parkinson's news 30 days in a row, is an even better way to get the word out. Not sure what to post? We can help with at least one idea.

WPC Organizational Partners, the European Parkinson's Disease Association and Parkinson's UK are launching the **#UniteForParkinsons** campaign on April 11 in honor of James Parkinson's birthday. Learn more about their campaign below and use their hashtag in the month of April to help unite the global Parkinson's community. This is a simple way to help raise awareness and doesn't cost you a penny!

While the WPC 2016 is in the rearview mirror for many after it ended five months ago, we are still reviewing the amazing talks that were given while in Portland. Thanks to **Biogen**, we have the funding necessary to turn 17 hours of talks into an online webcast program for your viewing pleasure! All the talks given at the WPC 2016 in the main plenary Hall C, including the Hot Topics, Plenary, Awards Ceremonies, Special Lunch panels and Daily Wrap-up talks were all taped and are now available for viewing. Below we share details on the plenary talk about stem cells and IPS cells. [Please take some time to watch the excellent webcast talks from Portland and forward this email to friends who were unable to attend.](#)

The WPC 2016 had a great team of WPC Blogger Partners who helped raise awareness about the Congress in the years before Portland. We are now looking for applications for WPC 2019 Blogger Partners. See the details below to learn how to apply and why it's a great way to contribute to the community. Our Blogger Partners are important WPC allies and their personal stories are often what inspire others to attend the WPC.

Since I'm on the topic of blogs, I want to let you know that the WPC will launch an official WPC Blog in April with posts written by guest bloggers as we count down to Kyoto, Japan. The WPC Blog will include posts by a wide cross section of past presenters, committee members and other Parkinson's experts. The WPC blog will have posts by neuroscientists, clinicians, rehab specialists, people with Parkinson's and others. We look forward to launching this in April and welcome your feedback. Stay tuned!

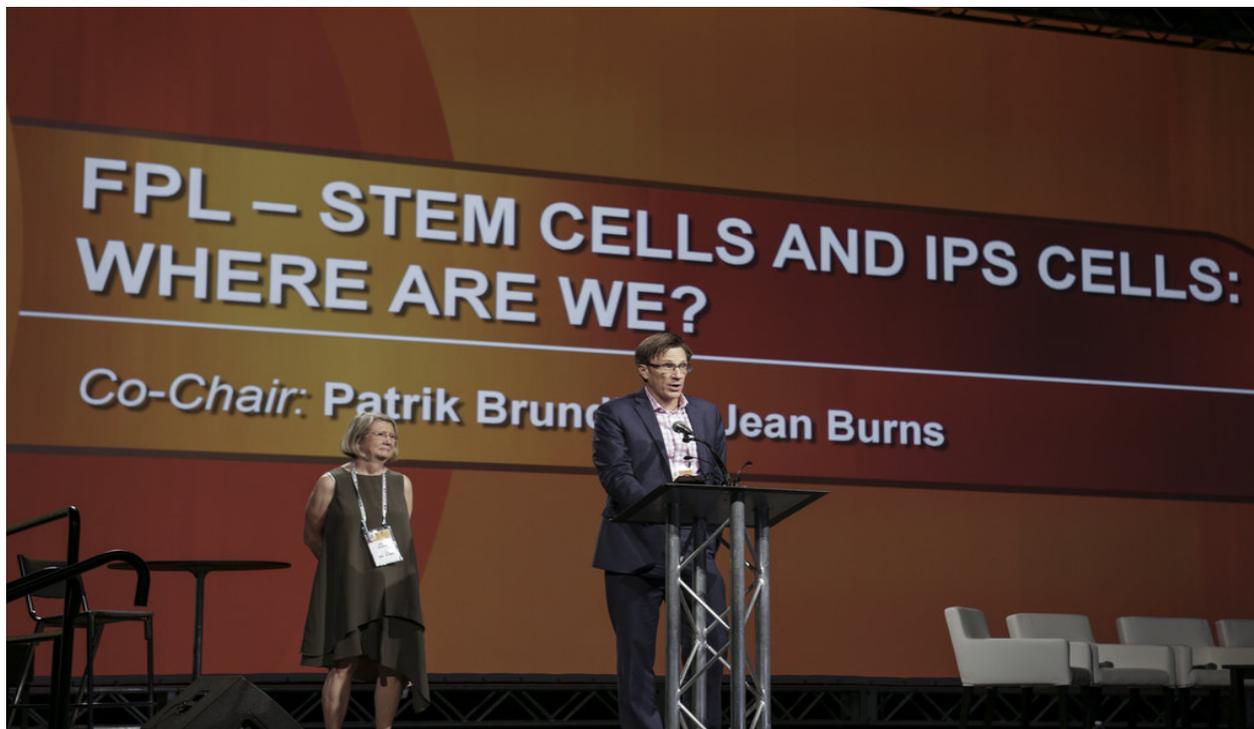
Kind regards,

Elizabeth "Eli" Pollard

P.S. Check out our tips below, from the *WPC 2016 Toolkit* on traveling with PD when using a Continuous Positive Airway Pressure Device.

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## **A Look Back at WPC 2016: *Stem Cells and IPS Cells: Where Are We?***



The final morning plenary at the WPC 2016 included four speakers who took a closer look at stem cells and IPS cells. Dr. Malin Parmar, Dr. Steve Finkbeiner, Dr. Roger Barker, and Tom Isaacs presented on the current state of clinical trials, the difference between stem cells and IPS cells, how to accurately assess the legitimacy of those online solicitations to join clinical trials involving stem cell therapy. [Watch Roger Barker's Presentation here.](#) If you like what you see, visit our webcast program to view the rest of the talks from this plenary and more!

In her talk Dr Parmar explained that there are two types of stem cells used in research for the treatment of Parkinson's and other diseases: Embryonic and (Induced Pluripotent Stem cells) IPS. IPS cells are created by reprogramming adult cells through the overexpressing of certain combination of genes to create stem cells. This makes it possible to generate patient specific cell lines. Creating these specific cell lines provides a better understanding of how the disease develops and progresses. In the future people with Parkinson's and other diseases may be treated using healthy versions of their own cells but the science is not quite there yet. There is some question going forward on which type

of stem cell is the best to use in human clinical trials. Both embryonic and IPS cells are capable of making different types of cells and have both been proved to make DA Neurons. However, it has not been clearly established that IPS cells are as effective as embryonic stem cells and it is uncertain how stable IPS cells will be overtime is unclear. Through clearly defined protocols in clinical trials, we can begin establish the efficacy of IPS cells. [See the slides from Dr. Parmar's presentation.](#)

Dr. Finkbeiner discussed ongoing efforts to create a fully human model of Parkinson's disease from a patient's IPS cells. Toxin models have not been predictive of success during clinical trials. Animal models are also not the best predictors because treatments may effect animals and humans differently. IPS cells can be used to create an effective model of the human brain in order to test new treatments. In order to create a successful IPS human model, program participation and donation of cells will be needed from people with Parkinson's and other neurological problems as well as a control population. Support for the research will also be needed from pharmaceutical companies. [See the slides from Dr. Finkbeiner's presentation.](#)

Dr. Barker spoke to the current state of cell therapy. The goals of cell therapy are to deliver dopamine in a regulated way that avoids dyskensia, psychiatric problems, cognitive problems, and other long term side effects. Past cell therapy trials have had widely varying results, leaving the overall efficacy of cell therapy unclear. This is due to issues with trial design, patient selection, and the process of immunosuppression post surgery. Attempts are ongoing to design better trials that will give clearer results for cell based therapies. [See the slides from his presentation here.](#)

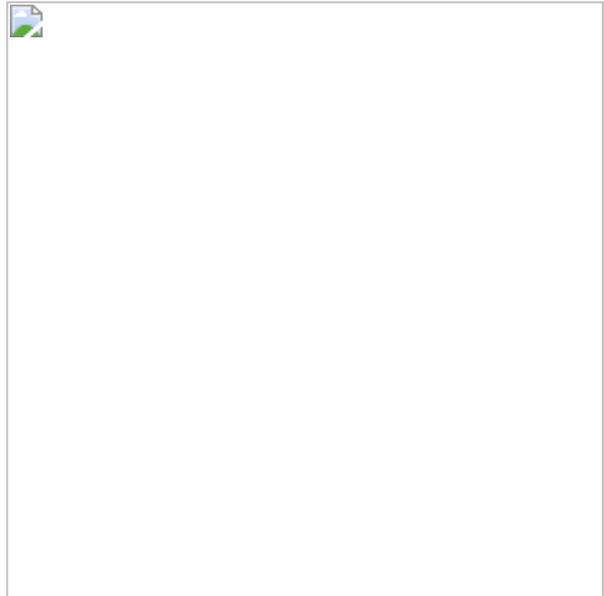
Tom Isaacs offered the perspective of a person with Parkinson's. As a person with Parkinson's it is difficult to find accurate and robust information on stem cell therapy. Scientists and regulators take a cautious approach when they discuss the long term outcomes but the internet is full of false claims of the benefits of stem cell therapy from private clinics. In order to counteract the lack of quality information and the overwhelming amount of spurious claims, it is essential that scientists, doctors and patients communicate clearly with each other. He kindly included a very humorous cynical patient's dictionary in his slides. [See the slides from his presentation here.](#)

**If you are considering stem cell therapy, Professor Barker recommends the [International Society for Stem Cell Research Patient's Handbook.](#)**

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**Become A WPC Blogger  
Partner!**

**#UniteForParkinsons – Join us on  
April 11!**



In the early stages of planning the WPC 2016, we launched the WPC Blogger Partner program and found 16 amazing bloggers in the community from four countries. The bloggers pictured to the right were our official partners for the WPC 2016. We are now looking for our next set of blogger for the WPC 2019. **Learn more about the requirements to become a WPC Blogger Partner.** Deadline to apply is Monday, April 3, 2017.

WPC Bloggers work closely with each other and the WPC to help identify interesting topics to cover leading up to and during the WPC.

### **APPLY TODAY**

## **Traveling with a Continuous Positive Airway Pressure Device (CPAP)**

*by Jean Burns & Alice Templin, BSc*

2017 marks 200 years since Parkinson's was recognized as a health condition. This April 11, on World Parkinson's Day, the European Parkinson's Disease Association and Parkinson's UK will launch a campaign to bring the global Parkinson's community together.

They are calling for everyone to use the hashtag #UniteForParkinsons on April 11 and to share experiences and plans for the future.

Why not #UniteForParkinsons in April? Using the hashtag on social media is the main call to action, but there are other ways to get involved. Learn more at [www.worldparkinsonsday.com!](http://www.worldparkinsonsday.com!)

- All spare batteries should be packaged in a way that protects them from short circuits and physical damage, e.g. exposed terminals can be taped over, each individual battery can be packed in a protective pouch or separate plastic bag, or the batteries can be transported in their original retail packaging.

- Pack an adaptor for the plane if required, as well as an adaptor suitable for the country you're traveling to. Adaptors can be bought from most electronics and travel stores, as well as in airports.

### **Checklist of important information that you should always carry with you:**

- Information about your health insurance plan and how to contact your doctor.



*Excerpt from the WPC 2016 Toolkit:*

### **Traveling with a Continuous Positive Airway Pressure Device (CPAP)**

Many people living with Parkinson's have sleep apnea and may require a CPAP device to get a good night's sleep. Should you bring your CPAP machine with you when traveling? Yes! It is an easy travel companion (lightweight and portable, with a universal power supply) and will give you the sleep you need, which is crucial to quality of life, especially when traveling.

#### **Using a CPAP Machine on a Plane**

Contact your airline if you plan to bring the machine on board with you, even if you will not be using it. Not all airlines permit the use of the CPAP machine on the plane. At least two weeks before traveling check with your airline regarding their CPAP policy and regulations. A medical certificate from your doctor and an FAA compliance letter may be required. There may be some restrictions on the types of machines allowed on the plane.

When you have received clearance from your airline to use your device on the flight be sure to:

- Carry a copy (or two) of their approval letter with you.
- Arrange to sit near a power source on the aircraft, if there is one available.
- Confirm the type of power cord or adaptor used by the aircraft.

#### **Before you leave home**

- A letter from your doctor certifying your need for positive airway pressure therapy.

- Specific information about the variables of your CPAP requirements: e.g. treatment pressure, mask type and size.

- Contact details for your equipment supplier and care provider.

- A device-specific airport authority FAA compliance letter supplied by the manufacturer.

#### **At the Airport**

- Portable battery-powered CPAP devices are accepted as carry-on baggage under specific size and weight conditions; check with your airline for their allowances. If the device exceeds the allowable size or weight, it must be transported as checked baggage.

- The security x-ray scanners will not harm your CPAP device. Usually, it gets scanned just like everything else; sometimes, airport security may remove it from its case to inspect it more carefully. Security may also need to see the medical statement from your physician verifying that you require and are carrying medical equipment.

- The in-seat power outlets in the aircraft are not designed for use with medical devices and may not be used to power your CPAP, BPAP or other medical devices during the flight, or to recharge the batteries for these devices.

- You can use your device on the plane, but not your humidifier; aircraft turbulence increases the risk of water spillage and damage to the device.

- If the plane does not have an alternate power source for your use, you will need a supply of batteries to last the trip.

- Most devices will automatically compensate for higher altitude changes; some lighter weight machines may require manual adjustments. If planning to use your CPAP on board, consult your provider about altitude compensation before you leave.

#### **On arrival at your destination**

- Use distilled or de-ionized water to fill your humidifier tub.

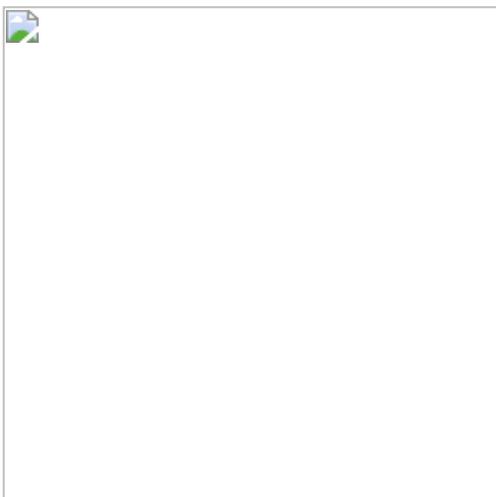
Preparing the CPAP Machine:

- Separate the main CPAP unit from the humidifier, drain the humidifier completely, and pack them separately in a supportive, well-padded carrying case or bag. Even if you don't plan to use your CPAP machine on the flight, take it on board as part of your carry-on luggage to reduce the risk of damage. It is a medical device, so may be taken on board in addition to your regular carry-on.

- Your hotel room may not have a power socket located near the bed head, so you may wish to pack an extension cord or be prepared to ask the hotel front desk for one.

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## Join us at the Parkinson's Unity Walk



The 23rd Annual [Parkinson's Unity Walk](#) will be held on Saturday, April 22, 2017 (Rain or Shine)

Sign up for a gentle 1.4 mile walk in Central Park and come to visit our WPC booth to enter our raffle and get your own Parky the Raccoon tattoo.

100% of donations to the PUW go to Parkinson's research at six major U.S. Parkinson's foundations.

In addition to raising awareness and funds for research, it will also be a day of community and education. We hope to see you there!

## New at the WPC Store!



We know that you have secretly had your eye on the Parky with the sleek black hoodie for awhile now. You've probably seen him on our [Instagram](#) or [Facebook](#) sharing advice from the WPC 2016 or just looking handsome. You can now have your own from the WPC store. All proceeds from Parky sales go towards travel grants for WPC 2019.

When you get one make sure to share your picture [here](#). We will add it to [whereisparky.org](#).

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